

***Who Cares?* Identifying, understanding, and supporting the work-life balance and wellbeing of students with caring responsibilities**

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Report

The student mental health network, SMaRteN, funded by UKRI (UK Research and Innovation), and led by King's College London, ran a consultation exercise 2019-20 to explore university students' views about future priorities for mental health research (SMaRteN, 2022). Approximately 400 students took part and among the research priorities identified was work-life balance and the impact of workload on students' wellbeing and experience (Sampson et al., 2022). *Who Cares?* led by a team based at the University of Lincoln with a researcher at the University of East Anglia, was designed by us in response to this funding priority announced in 2021 and aims to address the considerable gaps in sector knowledge about the work-life balance of students who care for children and/or for adults.

The Office for Students (OfS), the regulator for the Higher Education (HE) sector in England, UK, describes young adult carers in HE as a "*hidden*" minority about whom there is little empirical data (OfS, 2020). Research indicates that students with caring responsibilities (SCRs) may experience role conflict and stresses because of the tension between their educational and caring commitments. This struggle was particularly apparent during the lockdown periods of the COVID-19 pandemic such that the OfS identified student carers and students with children as amongst the most vulnerable student groups in terms of their mental health and wellbeing (OfS, 2020, p.3). The pressures faced by SCRs may impact upon their student engagement, experience, sense of belonging and their wellbeing, leaving them feeling lonely and excluded from their institution compared to other students (Dent, 2020).

Research aims

Who Cares? aims to:

- Develop the evidence base about the wellbeing and student experience of SCRs

- Improve understanding of the university journey for these students and the challenges of achieving work-life balance
- Identify practical ways to improve the support available for SCRs during their studies.

It seeks to address the following research questions:

- How do diverse SCRs experience the university journey?
- What is the relationship between feelings of engagement and wellbeing for SCRs?
- How can universities support and represent the interests of SCRs effectively?

Research Approach

Who Cares? has an explicit commitment to participatory methodological approaches, seeking to embed student voice and the tacit knowledge and experience of SCRs, student wellbeing professionals, HE staff and relevant third sector agencies in both the research design, implementation, and longer-term project legacy. Participatory Action Research (PAR) approaches have shaped the project's approach to stakeholder engagement and representation. Action research arises "*as people try to work together to address key problems in their communities or organizations*" (Reason and Bradbury, 2008, p.1). Drawing on the philosophy of Paulo Freire (1968/1970), a participatory orientation towards action research aims to work with (rather than for) marginalised and unheard communities to explore problems and arrive at practical solutions, empowering those communities through the process.

PAR explicitly recognises "*a plurality of knowledges*" (Kindon et al., 2007, p.9) which requires decentralising (though not devaluing) the privileged epistemological status of 'academic' knowledge and attributing equal status to other ways of knowing - in this case the tacit knowledge and lived experience of SCRs. To achieve this in practice, a project steering group was set up. Whilst predominantly made up of SCRs (n=12) other expertise are also recognised in the inclusion of professional service staff (n=2) involved in developing policies and interventions in support of SCRs, along with two academics with research experience in this subject. The *Who Cares?* team have provided flexible engagement options (including asynchronous participation and holding multiple iterations of the same meeting) to fit around studies and caring responsibilities and recompensed student steering group members with shopping vouchers. Student co-creation is at the heart of the project which embraces PAR approaches and the philosophy of 'Student as Producer,' conceived at the University of Lincoln (Neary and Winn, 2009). The project will develop new knowledge and resources shaped by the needs and priorities of SCRs. The following steps have also been taken to embed this approach within the study:

- Steering group members will be invited to contribute to project outputs
- Student steering group members are recompensed for their time and will be named on all future project outputs

- The project idea itself was student generated - research team members who designed the project have lived experience of studying whilst caring and mental health issues and/or conditions
- Feedback on the submission to the funder was sought from SCRs at the host institution
- SCRs will be supported to help shape the end of project symposium which will include an opportunity for members of the steering group to deliver presentations about the project and its findings with support from the research team.

Methods

The project methods are situated within the “*third research paradigm*” (Johnson and Onwuegbuzie, 2004, p.15), a mixed methods approach in which the benefits of collecting both quantitative and qualitative data are realised. The research follows an explanatory sequential design (Creswell and Plano-Clark, 2018), collecting quantitative data first, analysing that data and then utilising qualitative data to add explanatory depth.

The following instruments and procedures will be used:

- Desk research: a systematic review of the literature was carried out to examine existing research on this topic. A literature review protocol was devised employing the PICO model (Population, Intervention, Comparison, Outcome) developed for evidence-based reviews (Richardson et al., 1995). A broad typology of literature including peer-reviewed journal articles and grey literature was considered to explore the range of evidence and practices
- Survey research: an online questionnaire to ensure the voices and experiences of diverse SCRs are authentically represented. This includes a validated wellbeing scale - WEMWBS (Warwick Edinburgh Mental Wellbeing Scale). SCRs from any UK Higher Education Institution (HEI) were eligible to complete it and it was promoted widely on social media and through relevant networks including those of steering group members during 2022. The questionnaire data will enable analytical exploration of issues relating to wellbeing and belonging for diverse SCRs and for comparison of wellbeing to a baseline drawn from existing research on student wellbeing in HE
- Semi-structured interviews: preliminary analysis of the questionnaire data was used to help hone some of the topics to be explored in the interviews, in conjunction with input from steering group members. Semi-structured interviews with students from the target cohort will be undertaken next. Recruitment of 15 - 20 interview participants will produce rich data for meaningful analysis. The interviews will be recorded, transcribed and thematic analysis undertaken using the qualitative data analysis software, NVivo. SCRs from the steering group will contribute to the process of qualitative data collection and analysis as peer researchers.

Next steps

Through late 2022, the research team (including the student peer researchers) will complete the data analysis and seek feedback and insights from the stakeholder steering group to inform and critique the interpretation of the data. Numerous studies, particularly within the field of health research and evaluation, suggest that end-users should be involved in both the design and development of interventions (Van Deen et al., 2019). The steering group will continue to discuss dissemination of the findings and the project legacy, looking to maximise the benefits of the project for student carers and parents. Key priorities identified by the steering group are:

- To ensure project outputs are accessible to stakeholders, avoiding paywalled outlets and ensuring all resources are Open Access and written in clear, accessible language free from academic jargon
- To produce usable, credible, and transferable project outputs which will improve the experience of SCRs in HE
- To communicate project outcomes and recommendations directly to those who can make a difference to SCRs, for example, sector and institution-level policy makers and student support practitioners and tutors within universities
- To work with third sector agencies to support their advocacy for SCRs.

Summary

Who Cares? draws on the approaches and philosophies associated with both PAR and co-design to identify key challenges for SCRs in HE. With a particular focus on mental health and work-life balance for this often-overlooked student group, the project aims to work with a group of SCRs to understand and address some of these challenges. The authors look forward to reporting the research outcomes in 2023-24.

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For more information about the *Who Cares?* project, visit the SMARteN website: <https://www.smartn.org.uk/funded-research-2021.html> or follow *Who Cares?* on Twitter: [@SmartnWhoCares](https://twitter.com/SmartnWhoCares)

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